Medical Home and Care Coordination for Oregon Children and Youth with Special Health Care Needs

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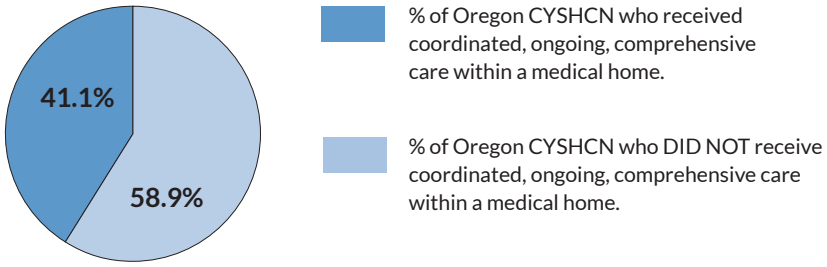
Children and youth with special health care needs (CYSHCN) require more care and services than other children. It is important that CYSHCN's care and services be coordinated, because their care can be especially complicated and costly.

CYSHCN who have a medical home are more likely to get the care they need. (See blue box for a description of medical home.) A lack of medical home is associated with more out-of-pocket costs for families, and fewer referrals to needed specialty care.[1]



Data Source: National Survey of Children with Special Health Care Needs, 2009/2010

Family-centered and easily-accessible care are core components of a medical home. Oregon families of CYSHCN report difficulty finding care that meets those standards. In 2011/12, 37% of Oregon CYSHCN received care that was not family-centered.[2] More than half the parents who responded to OCCYSHN's 2015 Needs Assessment survey said they had trouble getting quick and convenient appointments for their CYSHCN. They also reported long waits in the waiting room before appointments, which can be especially challenging for some CYSHCN and their families.

The Oregon Health Authority's Patient-Centered Primary Care Home (PCPCH) program sets standards that medical practices must meet to qualify as a medical home. Most of the PCPCHs in Oregon are located along the I-5 corridor between Portland and Eugene. Oregon CYSHCN who live elsewhere in the state are less likely to have access to a PCPCH.

What is a medical home?

Medical home is a way to offer primary healthcare. It is "a partnership between the patient, family, and primary provider in cooperation wtih specialists and support from the community."[3]

Medical homes offer care coordination and planning, easy access to advice and appointments, and a respectful environment where families of CYSHCN are included in decision-making. Care provided in medical homes is sensitive to the culture and language of patients and their families.[4]

It is especially important for CYSHCN to be served by a medical home. Their care extends beyond their family and the primary care clinic. They might require specialized doctors, speech or occupational therapies, mental health services. etc. Schools or social service agencies are often involved in addressing the child's needs.

A medical home provides a place to coordinate care, and to improve communication between all the people involved.

Medical home is recommended for children by the American Academy of Pediatrics and by the Affordable Care Act.

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There is a pressing need for better care coordination for Oregon CYSHCN. ***Forty-seven percent of families surveyed by OCCYSHN reported "rarely" or "never" getting as much help as they want coordinating their child's care.*** Thirty-four percent of Oregon CYSHCN did not receive one or more of the elements of effective care coordination:

- communication between doctors when needed
- communication between doctors and schools when needed
- families getting needed help coordinating care[2]

OCCYSHN's 2015 Needs Assessment identified communication issues as a barrier to effective care coordination. Communication problems were reported amongst professionals, and also between professionals and the family members of CYSHCN.

One way to support good communication and effective care coordination is to use a shared care plan. A shared care plan provides a central place to record information about a child's needs, and what is being done to address those needs. The plans help identify who will do what, and when. They allow families and providers to clarify goals and timelines together. When care plans are shared, the people and programs serving CYSHCN are more likely to work effectively together.[5]

Fewer than one third of parents surveyed by OCCYSHN reported that their child had a care plan. Of those, only half reported that the care plan had been shared with all the child's health care providers.

Shared care planning requires time and effort. Professionals and families must develop a process for creating, updating, and sharing the plans. While it is challenging, shared care planning offers the promise of improved communication and coordination on behalf of CYSHCN.

What is care coordination?

Care coordination is a central part of a medical home. Care is coordinated when a CYSHCN's family and the child's health and service providers communicate and work together effectively to meet the child's needs. Care Coordinators find resources for families, make referrals, and track progress on care plans. They help ensure good communication between CYSHCN, their families, health care providers, and community service providers.

The full report of the 2015 Needs Assessment findings from the Oregon Center for Children and Youth with Special Health Needs is available online at www.occyshn.org\|publications. This publication is available in alternate formats.

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[1] Boudreau, A.A., Goodman, E., Kurowski, D., et al. (2014). Care coordination and unmet specialty care among children with special health care needs. Pediatrics, 133, 1046-1053

[2] National Survey of Children's Health, NSCH 2011/2012. Data query from the Child and Adolescent Health Measurement Initiative. Data retrieved 12/23/2015 from www.childhealth.org

[3] Health Resources and Services Administration (HRSA). (n.d.). What is a medical home? Why is it important? Retrieved on March 16, 2015, from http://www.hrsa.gov/healthit/toolbox/Childrenstoolbox/BuildingMedicalHome/whyimportant.html.

[4] VanLandeghem, K., Sloyer, P., Gabor, V., & Helms, V. (2014a). Developing structure and process standards for systems of care serving children and youth with special health care needs. A white paper from the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs project. Washington, DC: Association of Maternal & Child Health Programs.

[5] VanLandeghem, K., Sloyer, P., Gabor, V., & Helms, V. (2014b). Standards for systems of care for children and youth with special health care needs. A product of the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs project. Washington, DC: Association of Maternal & Child Health Programs.